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A description of virtual skills workshops for supporters of loved ones with eating disorders: Indicators of benefit and acceptability, clinical reflections and consideration of neurodiversity

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Abstract

Objective: Providing information and support to those supporting a loved one with an eating disorder is a key part of evidence-based service provision. We report on how we took our workshops for supporters online during the Covid-19 Pandemic when country-side physical distancing restrictions meant we were unable to work face to face.

Methods: We outline the structure of an eight-session 2-h workshop series delivered fortnightly facilitated by a multidisciplinary team of clinicians, researchers and experts by experience. We use a repeated-measures design to understand the possible benefits of the workshops on supporter skills (n=76). **Results:** Measured using the Caregiver Skills Scale, we observed small-sized improvements in the overall skills (D=0.43) of n=17 supporters who provided data at the end of the intervention. Supporters gave largely positive feedback on the virtual format. They particularly liked the opportunity to interact with other supporters. As facilitators, we overcome our initial anxiety around workshop delivery using a new platform and reflected that having more time to cover key information and for skills practice over a period of 16 weeks offered opportunities to develop and reflect on new skill together as a group. We were also able to work with larger groups of supporters, as several barriers to access were removed.

Conclusions: As the workshops reached a larger number of supporters than through face to face delivery and were of benefit to those who reported on

Abbreviations: ASD, Autism Spectrum Disorder; AQ10, Autism Quotient (10 item version); CASK, Caregiver Skills Scale; ED, eating disorder; NHS, National Health Service; NICE, National Institute for Health and Care Excellence; PEACE, Pathway for eating disorders and autism developed from clinical experience; UK, United Kingdom.

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their skills, we plan to continue offering workshops to supporters online in future.

KEYWORDS

anorexia nervosa, bulimia nervosa, carers, eating disorders, motivational interviewing, psychoeducation

Key points

- The National Institute for Health and Care Excellence (NICE) Guidelines for eating disorders recommend that those supporting loved ones with eating disorders have access to information and support.
- Online workshops for supporters might remove barriers to access and increase uptake, and we wanted to learn more about this mode of delivery and its benefits on supporter skills.
- We were also interested in thinking about neurodiversity within the workshops, in particular whether supporters have traits of autism spectrum disorder. This information is important in helping us plan for more inclusive workshops.
- Around 1/3 of supporters scored over the cut-off on the Autism Quotient (AQ10) suggesting it is important to think carefully about how online workshops might benefit (or present challenges for) a more diverse group of attendees.
- Supporters reported benefits in terms of improvements in their skills and positive feedback at the end of one of five workshop series.

1 | INTRODUCTION

The National Institute for Health and Care Excellence (NICE) recommends that carers of people with eating disorders (EDs) receive information and support (National Institute for Health and Care Excellence, 2017). We choose to use the term 'supporters' because this implies an enabling role and is inclusive; indicating any loved one caring for a person with an ED. Caring for and upskilling supporters is needed for three key reasons. First, ED recovery, for some, can take many years (Fernández-Aranda et al., 2021) and carers contribute a substantial proportion of the care often needed in order to overcome the illness (Anastasiadou et al., 2014; Highet et al., 2005). The significant practical, social and emotional support provided by supporters (Padierna et al., 2013) helps to compensate for the cognitive and socio-emotional challenges and isolation associated with the illness (Harrison et al., 2014; Treasure et al., 2020). Second, supporters themselves report their caring role significantly impacts their own functioning (Linacre et al., 2015; Maunder & McNicholas, 2021). This can include experiences of depression, anxiety and social isolation (Graap et al., 2008; Zabala et al., 2009). Third, EDs evoke strong interpersonal reactions in supporters

which can inadvertently perpetuate the illness (Treasure et al., 2020; Treasure & Todd, 2016). Professional skills training helps supporters modify these reactions and equips them with communication tools aimed at reducing confrontation and supporting behavioural change in the person with an ED (Treasure & Nazar, 2016). This is a key component of collaborative caring within the New Maudsley Model (Treasure et al., 2016).

A systematic review and synthesis of 28 studies on the impact of interventions for supporters of loved ones with EDs found supporters benefited from working with peers in a group setting and felt more equipped to help manage the disorder (Hannah et al., 2021). This has led to many services, including our own, delivering skills-based workshops for supporters as part of usual care (Pépin & King, 2013).

Before the Covid-19 pandemic began in early 2020, our service (a specialist adult, inpatient unit for EDs in London, UK) ran full-day, face to face workshops for supporters which took place about once every 6 weeks, informed by the family workshops outlined by Whitney et al. (2012). When the UK government instructed citizens to remain at home and limit face to face interactions as measures to manage the outbreak, an

obvious solution was to offer the workshops online instead. While digital treatment provision is becoming more widely available in mental health settings (Linardon et al., 2020), and during the pandemic there has been a move towards the use of telehealth (Garfan et al., 2021), we wanted to think carefully about how to deliver key elements of our workshops in a virtual space. As a team, we felt that the challenge we were presented with also offered a significant opportunity to engage with a more diverse group of supporters, particularly those supporting loved ones with comorbidities and those who may have found it inconvenient or too costly to attend in person. As our service has been developing a new pathway for people with EDs and an autistic spectrum disorder (ASD) diagnosis or traits (please see peacepathway.org for more information), because this is a common comorbidity that has previously been poorly understood (Kinnaird & Tchanturia, 2021), we also saw this as an opportunity to understand more about ASD comorbidity in this work. We felt this was one way of starting to address the finding that supporters looking after loved ones with ASD and EDs have experienced a lack of support from healthcare services (Kinnaird et al., 2021), but little is known about whether supporters themselves might present with ASD traits and might need some adaptations to the support that we provide for them. Neurodiversity is often thought about in the adolescent literature (Schröder et al., 2022) and is less well researched in adult patients and their adult supporters.

This paper aims to explain how we adapted our workshops to deliver them online. To understand more about the needs of supporters who might attend virtual workshops, we also describe clinical demographic variables for the sample, including a measure of ASD traits. To understand whether the skills workshops delivered in a virtual format might have possible benefits for supporters, we also use service audit data to explore how the workshops might improve supporters' skills. As a multidisciplinary team of clinicians, an expert carer, an expert patient and researchers who have contributed to delivering components of the workshops and supported their delivery through clinical supervision, we will discuss what we learnt from taking the workshops online. Finally, we will outline our plans for the future in relation to this key component of our service provision.

It was hypothesised that there would be an improvement in carer skills, measured using the Caregiver Skills Scale (CASK; Hibbs, Rhind, Salerno et al., 2015) after, compared to before attending, a workshop series consisting of eight 2-h sessions.

2 | METHODS

2.1 | Design

A repeated-measures design was used. Carers were asked to complete outcome measures before and after attending a workshop series.

2.2 | Participants

The workshops were advertised to and were open for any supporters whose loved ones were receiving treatment for an ED in any of the South London and Maudsley NHS Foundation Trust adult ED services. This included outpatient, inpatient and day-patient services. During the Covid-19 pandemic, our service, like many ED services, received an increase in referrals and re-admissions. As we were able to provide more immediate support to the supporters of patients on the waiting list for individual therapy, we also made the workshops open to this group. We took a very flexible and inclusive approach and did not prescribe any further limitations of attendance with regards to age, but asked supporters to commit to attending as many workshops as they were able to within the series they had signed up for. If a supporter's loved one was admitted to one of our services partway through a workshop series, they were offered the opportunity of joining mid-way and then attending the sessions they had missed once the next series began. Alternatively, they were also welcome to wait until a new series started. During the course of this project, there were some changes to the way that the service was run which meant we became allied with another large ED service in London at St George's Hospital. Therefore, the final series was also advertised to supporters whose loved ones were receiving treatment within this service. We also promoted the workshops to supporters whose loved ones were accessing our PEACE pathway, a pathway for people with an ASD diagnosis or for people with ASD traits across our inpatient, outpatient and day-care services. This was an important opportunity for us to think more about the needs of supporters whose loved ones were accessing this pathway.

2.3 | Measures

2.3.1 | Caregiver Skills Scale [CASK (Hibbs, Rhind, Salerno et al., 2015)]

We used this measure to audit the possible benefits of the virtual workshops. This 27-item scale asks respondents to

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rate their degree of confidence across a range of caregiving skills using a scale ranging from 0 to 100, ranging from almost never to almost always. Higher scores indicate higher confidence. The tool provides a total score and six subscales: Bigger Picture (the ability to take the long view and not get caught up in the details of the illness); Self-Care (strategies to improve carers' own mood and resilience); Biting-Your-Tongue (not getting caught up in nagging and bickering about the illness); Insight and Acceptance (the ability to recognise symptoms as part of the illness and to not personalise the behaviours); Emotional Intelligence (the ability to regulate emotional reactions, despite being provoked and to have empathy for the other); Frustration Tolerance (to be able to withhold getting drawn into conflict about aspects of the illness). The CASK overall score has good internal consistency (Cronbach's α was 0.92 and 0.95 for mothers and fathers, respectively (Hibbs, Rhind, Salerno et al., 2015) and was 0.93 in this study.

2.3.2 | Autism Quotient [10 item version; AQ10 (Allison et al., 2012)]

This 10-item self-report measure has a 4-point Likert scale ranging from definitely agree to definitely disagree. It addresses key ASD traits including social communication, attention switching, attention to detail and imagination. Higher scores indicate the presence of ASD traits and a cut-off of ≥ 6 is used to indicate the presence of ASD traits that may warrant further investigation. We included this measure to better understand whether supporters themselves reported ASD traits, with the aim of understanding more about the presence of neuro-diversity within workshop attendees. Cronbach's α for our sample was 0.8.

2.3.3 | Open-ended items

At the end of each workshop series, we asked supporters to provide feedback in response to the following questions: (1) What did you like most about the workshops; (2) How could we improve?

2.3.4 | Intervention outline

This audit reports on five workshop series. Within each workshop series, the learning materials were structured as outlined in Table 1. Each series contained eight workshops which ran fortnightly for 2 hours on Microsoft Teams or Zoom. Readers can find comprehensive

guidance and all the necessary materials needed to run their own workshops in the New Maudsley Skills-Based Training Manual (Langley et al., 2018).

2.4 | Adaptations for an online setting

2.4.1 | Content and structure

We aimed to cover the same material in the virtual workshops that we had previously covered in our oneday, in-person workshops. These workshops always covered information about EDs, particularly thinking about interpersonal maintenance factors using animal metaphors (please see https://newmaudsleycarers-kent. co.uk/wp-content/uploads/2019/01/Worksheet-3.pdf for an explanation of these). We use these metaphors to explain supporters' responses to ED symptoms. The inperson workshops also taught communication skills using motivational interviewing techniques. However, in our online workshops, we took the opportunity to allow more time for to discuss each topic because we had 16 learning hours across the eight 2-h sessions, and to provide opportunities for skills practice. This format was also informed by the framework for skills workshops described by Langley et al. (2018) whose manual discusses how to deliver skills training for supporters across a series of shorter sessions. To this end, we didn't add in any new content beyond what is typically delivered in skills-based workshops described well by Langley et al. (2018), Whitney et al. (2012) and Goddard et al. (2011), but we did provide more space for skills practice, as this was always the key piece of feedback we had received when delivering the material across a oneday format - that people wanted more time to practice and refine their skills.

The workshop themes were informed by the TRI-ANGLE materials (Cardi et al., 2017) which are guided self-care materials focussed on increasing understanding of EDs and communication skills developed for supporters of people with EDs and had already been delivered in an online format. Initially, we included the session on *Identifying your own strengths and resources* (session 6) earlier on in the series, in the session 2 slot. We learnt that supporters got more out of this material when they had gotten to know each other better and felt more able to speak about themselves in a group and how the illness had impacted them.

The first workshop session of each series started with introductions and a discussion around hopes and expectations. Subsequent workshop sessions began with introductions of any supporters who were joining for the first time, and a review of skills that supporters had tried

TABLE 1 Workshop protocol

Session	Theme	Content	Key components
1	Understanding the complexity of an eating disorder	The first session begins with a discussion about expectations for the workshop series. Carers are introduced to the cognitive interpersonal maintenance model and the importance of supporters' role in their loved one's recovery. Discussion about why it may be difficult for their loved one to change, and challenges faced in trying to facilitate this. Psychoeducation about negative automatic reactions to eating disorders. Animal metaphors are introduced, and ideas of creating a calm, curious, compassionate, caring environment to practice and develop new communication skills	Psychoeducation about biopsychosocial factors in eating disorders (knowledge)
2	Noticing and managing emotional reactions to the eating disorder	Recap of the cognitive interpersonal maintenance model. Psychoeducation about emotions and the role they play in eating disorders, with a focus on fear, disgust and shame. Discussion about the impact these emotions have on supporters. Skills training on how to effectively respond to emotions using emotion focussed family therapy skills (for example, demonstration through role play of noticing, labelling and validating emotions and how to meeting the emotional need and soothe loved ones)	Psychoeducation. Sharing the cognitive interpersonal maintenance model as a formulation. (Knowledge, support, skills practice)
3	The importance of building trust and compassion	Discussion guided by examples from an expert carer and patient on how the eating disorder affected trust in their relationship and how these changed across the course of recovery. Opportunities for supporters to discuss their own experiences. Forum to explore ways of rebuilding trust through enhanced understanding and communication skills	Reducing hostility and confrontation; increasing compassion (knowledge, support)
4	Increasing resilience: How do you respond to the eating disorder?	Sessions four and five focus on sharing motivational interviewing skills with carers. Supporters are introduced to the transtheoretical model stages of behavioural change in eating disorders (Wilson & Schlam, 2004) to understand sort of communication skills might be useful and different stages of change in eating disorder recovery. Supporters are shown, through role plays, the motivational interviewing skills of open questions, affirmations, reflections and summaries (OARS) and given chance to practice these with each other	Skills practice
5	Supporting change by using compassionate communication skills	Recap of OARS. Further opportunities to practice motivational interviewing skills in smaller groups. Role play by facilitators to demonstrate these advanced communication skills	Skills practice.
6	Identifying your own strengths and resources	Discussion about the important of self-care within the caring role, with examples from an expert carer. Psychoeducation from positive psychology of ways to enhance self-care/Opportunities to reflect on what supporters might do differently	Recognising the impact of caring for a loved one; supporting self- care (support)
7	Nutritional recovery and meal support	Education about the effects of starvation on the body and brain and nutritional rehabilitation in recovery. Supporters learn about regular eating and the use of a meal plan in recovery. Psychoeducation and discussion about how to support loved ones during mealtimes, when eating out, portion sizes, and helpful/unhelpful	Psychoeducation (knowledge, support, skills practice)

TABLE 1 (Continued)

Session	Theme	Content	Key components
		language around food. Supporters were encouraged to share practical meal support skills and discuss learning around nutritional support at different stages of their loved ones' recovery	
8	Sustaining progress in recovery over time	Discussions about the transitions faced by loved ones and how these life cycle events can be affected by eating disorders. Discussion around why these transitions may be more challenging because of the eating disorder and how this impacts supporters. Psychoeducation about SMART goal setting as a tool for planning for change. The last session closes with a discussion about overall learning from across the workshop series, including information about what further support attendees may want or need	Relapse prevention. (Psychoeducation, skills practice)

Note: Key components are highlighted in relation to interpersonal reactions evoked by eating disorders which the Cognitive Interpersonal Maintenance Model (Treasure et al., 2020) suggests inadvertently maintain the eating disorder and to the NICE Guidelines which recommend supporters receive information and support. You can view our materials/resources here: https://www.notion.so/Carers-Workshops-Materials-a5e9b64af5644fd7a3b7a228eec72c03 Supporters refers to anyone looking after a person with an eating disorder; loved one refers to the person with the eating disorder.

and what they had learnt. This gave an opportunity for the group to get to know each other, which we felt was more important to focus on in a virtual space; it also provided continuity between the workshop sessions within a series which were held fortnightly, and finally, we felt that this offered an important opportunity for attendees to capitalise on new learning and plan their next steps. At the end of each workshop session, we allowed 10–15 min for each supporter to summarise a new piece of learning acquired during the workshop session.

2.5 | Online tools

We thought about the range of tools possible in the online space to facilitate learning within the virtual workshop format. These included breakout rooms, digital sharing of materials and use of cameras, microphones and online gestures to facilitate conversation.

2.5.1 | Breakout rooms

We used breakout rooms to enable supporters to work together in smaller groups to practice skills. We made particular use of this tool in workshops 4 and 5 where we focussed on developing new communication skills (motivational interviewing). In these rooms, there was no facilitator present, but we invited supporters who needed help with particular aspects of the skills they were practicing to call in a facilitator using the 'call for help'

feature. This was well used and was a good way for supporters to get feedback and assistance in a smaller group setting. The breakout rooms were set up so that three supporters would work together. We encouraged them to take turns practicing being the supporter and using motivational interviewing skills, with the second person playing the role of a loved one with an eating disorder and the third person being an observer who could step in and help the supporter and was asked to provide feedback on the skills they had observed the supporter using. We set the breakout rooms to randomly allocate supporters to these smaller groups which meant that they could meet and work with different people each time this tool was used.

2.5.2 | Digital sharing of materials

We provided slides on a website so that supporters could look at these in their own time and keep them for their own learning. We found this saved time in having to email attendees before each workshop. We also thought this might help to give supporters an overview of workshop session content across the 8 sessions within each workshop series.

2.5.3 | Use of cameras and online gestures

We encouraged supporters to turn on their cameras and participate as much as possible by joining in discussions either verbally or through using the chat function. We didn't introduce any breaks into the sessions, but let people know that they could take a break when needed and could have a camera break if this helped them during the session. We were particularly mindful of neurodiversity here and felt it important to let supporters manage their engagement in a way that worked best for them. We encouraged supporters to mute themselves unless they were speaking when we were working together in a larger group to reduce background noise and interference, again being mindful of any possible sensory differences that supporters might bring to their experience of the workshops. We invited supporters to use online gestures such as the raising their hand when they wanted to speak so that we enable all supporters who wished to contribute in an active way to have their voices heard. We always explained this etiquette at the start of each workshop session so that supporters had a clear idea of how to engage with this virtual format.

2.6 | Procedure

Supporters were invited to register for the workshops after seeing an advert within the service. Initially, they were asked to email the lead facilitator (AH) to register, but over the course of this project, we looked to a tool to help us to automate some of the administration around the workshops. For the final three workshop series, we asked supporters to register for each series using the Eventbrite platform. Prior to the first workshop within each series, supporters who had registered were sent a link to a survey containing the questionnaires on the Qualtrics platform. After the final workshop, they were sent a new link and asked to respond to the postworkshop questionnaires and give their feedback on their experiences of the workshops. During the final series, we were successful in obtaining funding from King's College London to reimburse supporters for the time taken and expertise they shared through completion of the measures. If they completed both the before and after workshop measures, they were offered a £20 gift voucher.

The project underwent ethical review by the King's College London Research Ethics Committee.

2.7 | Data analysis

Data were analysed using SPSS (version 26). Data from the CASK were inspected using boxplots, histograms and the Kolmologrov-Smirnov test. These plots suggested normal distribution for the CASK total score before and after the workshops. The Kolmogorov-Smirnov test

indicates that CASK total scores before the workshops do follow a normal distribution (D(76) = 0.096, p = 0.178) before the workshops and after the workshops (D (16) = 0.185, p = 0.1147). Therefore, paired *t*-tests were used to compare means from before and after the workshop for the CASK total score and the bigger picture, selfcare, biting your tongue, insight and acceptance and emotional intelligence subscales. Means, standard deviations and 95% confidence intervals are provided for the CASK before and after the workshop. An estimation of effect size is provided using Cohen's D. An effect size estimation of 0.2 indicates a small effect, 0.5 indicates a medium effect and 0.8 indicates a large effect. To correct for type 1 error in the context of multiple testing, the Bonferroni correction (0.05/6) was applied, with an adjusted p value of 0.0083.

3 | RESULTS

One hundred and 39 supporters registered to attend a workshop series, representing an average of 28 supporters at each workshop series. Seventy-six supporters provided data after attending one of five workshop series with 8 two-hour fortnightly sessions, which took place online between November 2020 and April 2022. Supporters attended a median of 6 (out of 8) workshops within each workshop series (IQR = 1; minimum = 2, maximum = 8).

3.1 Data on workshop attendees

Data in Table 2 show that most supporters were female parents, with White British ethnicity and were caring for a loved one with anorexia nervosa. Supporters' loved ones were, on average, in their late 20s with an enduring form of illness. There was good representation across the inpatient, day-patient and outpatient service provision.

One supporter reported that English was not their first language (their mother tongue was Afrikans) and one supporter reported that for their loved one, English was not their first language (their mother tongue was Finnish). As we opened the workshops to supporters from another London ED service working in alliance with our own service during the final workshop series, two supporters in the final series had loved ones receiving treatment in this setting. One supporter told us that their loved one was being treated within the PEACE Pathway, but in total 4 (5.26%) supporters said that they thought their loved one might have an ASD diagnosis and 4 (5.26%) reported that their loved one had a diagnosis of ASD confirmed by a multidisciplinary team. The

TABLE 2 Demographic information on supporters who registered for the workshops (n = 76)

Domographic variable	Catagory or group	Dogovintivo data
Demographic variable	Category or group	Descriptive data
Supporter gender	Male	7 (9.21%)
	Female	36 (47.37%)
	Not provided	33 (43.42%)
Supporter ethnicity	White British	35 (44.74%)
	Irish	4 (5.26%)
	White European	2 (2.63%)
	Mixed ethnicity	3 (3.95%)
	Not given	33 (43.42%)
Supporter age	Mean (SD)	55.17 (11.05) Minimum = 20; maximum = 77
Supporter's relationship with	Parent	68 (89.47%)
their loved one	Husband/wife/partner	3 (3.95%)
	Friend	1 (1.32%)
	Sibling	2 (2.63%)
	Child	2 (2.63%)
Loved one's gender	Male	0 (0%)
	Female	74 (97.37%)
	Non-binary	1 (1.32%)
	Not given	1 (1.32%)
Loved one's ethnicity	White British	68 (89.47%)
	Irish	2 (2.63%)
	White European	1 (1.32%)
	Mixed ethnicity	5 (6.58%)
Loved one's age	Mean (SD)	27.95 (12.31)Minimum = 18; maximum = 60
Loved one's duration of illness (to the nearest year)	Mean (SD)	8.91 (10.05)Minimum = 1; maximum = 34
Loved one's current eating disorder	Anorexia nervosa	59 (77.63%)
diagnosis	Bulimia nervosa	7 (9.21%)
	Binge eating disorder	2 (2.63%)
	Other specified feeding or eating disorder	4 (5.26%)
	Diagnosis not known to the supporter	4 (5.26%)
Type of treatment currently being	Inpatient	32 (42.11%)
received by	Outpatient	22 (28.95%)
the supporter's loved one	Day-care	10 (13.16%)
	Waiting list	10 (13.16%)
	Not known to the supporter	

Note: SD, standard deviation. Responding to questionnaire items was voluntary and we did not force responses within Qualtrics, therefore data are missing for some variables and percentages reflect the full sample (n = 76). Data on supporter age was missing for n = 11 supporters. As 'mixed ethnicity' lacks useful information, we asked carers to give further details. With regards to their loved ones, two supporters specified their loved one's ethnicity as follows: White British/Black Caribbean and English/Nepali. Across the five workshop series, 139 supporters registered to attend, representing an average of 28 supporters at each workshop series. These data represent those who opted to complete the outcome measures. Supporter refers to a person caring for someone with an eating disorder; loved one refers to the person with the eating disorder.

remaining 68 (89.47%) supporters said that their loved one did not have ASD comorbidity. A subgroup of 23 carers (30.26%) reported on their own ASD traits measured by the AQ10. The mean score was 4.71 (2.85); minimum = 1; maximum = 9. Eight supporters (representing 34.78% of those who completed this measure) scored above the suggested cut-off for possible ASD on this measure.

3.1.1 | Caregiver Skills Scale (CASK) outcome variables

The data on the CASK in Table 3 show that after the workshops, carers reported increases in their confidence in their caregiving skills. There is a small-sized, albeit non-significant overall improvement, indicated through the CASK total score and in particular, there is a small-sized, significant improvement in supporters' confidence in their ability to care for themselves.

3.2 | Facilitator learning—Our reflections as a multidisciplinary team of experts by experience and professional training

In the section below, in Figures 1–3, we offer a summary of our learning after running five series of the workshops online.

Table 4 provides qualitative feedback from supporters (n = 27) who responded to the opportunity to provide detailed feedback. The feedback has been organised into categories to facilitate interpretation.

These useful comments suggest the online format worked well, although this was not expressed by all supporters with one asking for a return to the face to face setting. A key learning point was the support offered by the presence of other supporters. As a team, we felt this was created through each series taking place fortnightly over eight sessions which really gave supporters an opportunity to get to know each other. This was typically missing in our original one-day workshops where there were fewer opportunities for this sort of networking.

4 | DISCUSSION

Research and clinical experience shows the importance of involving patients' supporters in their care (Treasure et al., 2021). This audit aimed to discuss how we adapted our workshops for supporters to an online format through the experiences of a multidisciplinary team of clinicians, researchers, expert carers and patients. A further aim was to understand the possible benefits of the workshops on caregiving skills and to use attendee feedback and our experiences as facilitators to think about how to further develop the workshops. We were also interested in understanding neurodiversity within

TABLE 3 Data from supporters on the Caregiver Skills Scale (CASK)

	Before the workshop series n = 76	After the workshop series n = 17	Paired t-test result
Bigger picture subscale (mean/SD/Lower and upper bound of	57.43 (16.03)	65.54 (13.68)	t(16)-2.129, $p = 0.049$; $D = .49$
the 95% confidence interval)	48.55-66.30	57.95-73.11	
Self-care subscale (mean/SD/Lower and upper bound of	49.50 (15.21)	62.83 (12.57)	$t(16) = -3.928, p = 0.001^*; D = .42$
the 95% confidence interval)	41.08-57.92	55.87-69.79	
Biting your tongue subscale (mean/SD/Lower and	51.11 (18.81)	59.11 (18.88)	t(16) = -1.532, p = 0.145, D = 0.21
upper bound of the 95% confidence interval)	40.70-61.52	48.44-69.56	
Insight and acceptance subscale (mean/SD/Lower and	58.44 (19.23)	56.00 (24.86)	t(16) = 0.145, p = 0.886, D = 0.01
upper bound of the 95% confidence interval)	47.81-69.09	42.24-69.76	
Emotional intelligence subscale (mean/SD/Lower and	56.67 (14.07)	57.33 (21.45)	t(16) = -0.121, p = 0.905, D = 0.02
upper bound of the 95% confidence interval)	48.88-64.46	45.45-69.21	
Caregiver Skills Scale total score Mean/SD/Lower and	57.26 (12.11)	63.61 (14.38)	t(16) = -2.991, p = 0.01, D = 0.43
upper bound of the 95% confidence interval	50.55-63.96	55.64-71.57	

^{*}Indicates a significant difference after correction for multiple testing.

Hosting workshops online felt really daunting at first. Getting to grips with the technology and managing the invites that needed to be sent out to supporters provided opportunities for new learning. I grew more confident after each workshop. I saw significant benefits of the virtual setting. Some supporters joined from their car, their workplace; even a caravan in one case. This meant the workshops became more inclusive and fitted more easily into busy people's lives. Attendance was always higher than our face to face workshops which typically involved between 3 and 9 supporters. I learnt to use Eventbrite as a tool to manage communication with supporters and to register their attendance. As the skills-based learning was spread out over 16 hours rather than one day, this meant there was more space for the group to get to know each other; for people to practice skills in between workshops and for supporters to offer peer support to each other. Some downsides include excluding those without access to a computer/phone/tablet and the internet. However, I started the first series thinking *I can't wait to do this in person again* and ended that first series thinking *why would I run workshops in person again*?

FIGURE 1 Reflections from a clinical psychologist with expertise in delivering the workshops (AH)

our supporter cohorts to help us consider the broader needs of supporters and how to make the workshops more inclusive when developing them further in future. This is important work to think about in the context of working with supporters, to go alongside the adaptations to interventions that have been discussed for neuro-diverse patients with EDs (Li et al., 2021).

The hypothesis, that there would be an improvement in carer skills, measured using the CASK after, compared to before attending a workshop series, was partially supported by the data. There was a small-sized increase in carer skills which did not survive correction for multiple testing. Supporters reported small-sized improvements in their skills measured by the CASK bigger picture, biting your tongue and self-care subscales, but there were negligible changes in the emotional intelligence and acceptance and insight subscales. In future workshops, we will place more emphasis on developing emotional intelligence and insight into the eating disorder and its impact on supporters. Supporters also provided positive feedback, saying that they had a new understanding of EDs and learnt new skills and they

particularly emphasised how they had benefited from a learning environment with other supporters present. These findings corroborate the moderate-sized improvements in carer wellbeing observed in a systematic review and meta-analysis of these workshops delivered in-person (Hibbs, Rhind, Leppanen, & Treasure, 2015), suggesting that online delivery may produce similar effects to inperson learning.

It was interesting to observe that the median number of workshop sessions attended was 6 (out of a maximum of 8), and we examined our registers to explore whether attendance at any particular session was higher or lower than others. There wasn't a specific observable pattern, possibly indicating that non-attendance was more related to personal circumstances than like or dislike of any of the session topics which were provided in advance to supporters. This is a point supported by the communication we had with supporters when they let us know they were unable to attend. Their reasons for missing sessions typically related to needing to attend other appointments, or work commitments that prevented them from joining a particular session.

When I was asked if I might consider joining the carer workshops as an expert by experience, I felt a mixture of nervousness, excitement and curiosity. My own experience of the illness comprised many years of support across various different services. Since leaving services, one thing I have reflected on is how much I wished I could have spoken to / met others who were further along their journey, as the illness isolates you and prevents you from seeing the possibility of recovery.

During the workshops, I shared some of the positives and negatives of my own experiences, in line with the workshop content. I found it interesting to see the value of the lived experience perspective, which enabled myself and my mother to support the facilitators and attendees to consider things that are perhaps less thought about, such as moving to university (and the impact on my own recovery and my family's wellbeing), managing familial and intimate relationships, and the pros/cons of meal plans.

Although I was very nervous about how much to share and about saying the right thing, I always felt welcomed by the group. Every question I received was genuine and thoughtful. I witnessed the value not only of the psychoeducation and skills training elements of the group, but also, and perhaps most importantly, the value of peer support, seeing carers supporting one another. Attendees were all at different stages of their journeys, but what drew them all together was a resilience and desire for their loved one to get well.

FIGURE 2 Reflections from an expert patient who co-facilitated the workshops (HW)

One significant advantage of running the workshops online is that it removes the barrier to attending inherently present in having to travel to a particular place. This could benefit people with mobility differences, working parents who may have had to leave a full day, in person workshop early in order to collect children from school and those caring for elderly loved ones who may find it easier to cover 2 h of their caring work than a full day plus travel time. It also removes travel costs, further increasing accessibility. As several facilitators had been involved in running in-person workshops in the past, one

of our key reflections was the increase in uptake for the online workshops where we worked with between 12 and 21 supporters in each workshop series, compared to when we ran them in-person over the course of a day and generally worked with between 3 and 8 supporters. This suggests online workshops are potentially more acceptable to supporters and more feasible to attend, and this also has potential cost-saving implications for the service, because we were able to support more people at the same time. The use of breakout room, which some supporters fed back they liked and wanted more of, meant that we

I have been assisting at the carers' virtual workshops since they began in lockdown and it has been really encouraging to see how well they have been supported. I have lived experience of caring for my daughter throughout her ED and I decided to help at the workshops above all to give other carers the hope that things can and do change. I also wanted to share my experience and coping strategies and to show that there is no single way to support a loved one with an eating disorder.

I have previously attended several in person carers' workshops so it has been interesting to make the comparison between the online workshop and the face to face workshop. I have also volunteered at a face to face workshop.

Attendance at the online workshop has been higher than the face to face workshops, in part driven by extending it to include outpatients and day care services and carers with loved ones on a waiting list. Carers appreciated being able to attend online and be anywhere in the country. I think the fortnightly two hour sessions worked well rather than a full day at the face to face workshops. So this may be a better way to engage with families. I also felt that some carers opened up more at an online carers group that they might at a face to face workshop.

The sessions where my daughter and I were in the same session talking about our lived experience (as a loved one and a carer) seem to be really well received. It was an emotional experience for me as a carer to see my daughter talk so openly and honestly about how destructive and all controlling her illness was. We also had a male service user attending some sessions and his insight and honesty was well received by the group. I wonder whether this has been easier to do online rather than face to face, given how emotionally charged these reflections can be.

FIGURE 3 Reflections from an expert supporter who co-facilitated the workshops (JW)

could also work more intensively with smaller groups of supporters to help them develop new communication skills. As workshop organisers, we found it really helpful to use a platform like Eventbrite to streamline the way we sent out workshop invites and communicated with supporters. This is a new practice we will adopt in future workshop delivery.

It was interesting to note that 34.8% (n=8) of supporters who completed the AQ scored over the cut-off, suggesting the possible presence of ASD/ASD traits.

TABLE 4 Qualitative feedback from supporters attending the workshops

Feedback Category	Supporter comments		
General feedback	Course was really helpful and think essential for any carersThese workshops are really valuable. Please continue to run themIt is a heart-breaking time for carers and the workshops helped us feel supportedThe workshops were interesting and informativeI didn't like the content on nutrition because I don't eat with my daughter—she lives in another city.		
Reflections on online delivery	I liked the on-line formatPersonally l think everyone should have their cameras on during the calls, except for short necessary breaks, so we can have a connection instead of looking at a blank screenIt would have been nice to do them face-to-face		
Benefits of working together with other supporters	Good participation and honesty from CarersMeeting other carersHearing others experiences and what works for themSense of solidarity with other parents only those going through it can really get itNot feeling "alone" in dealing with i Everyone could readily chip in with commentsBeing able to talk to other parentsIt was helpful to hear other carers experiences		
Role of a multidisciplinary team of facilitators including people with lived experience of eating disorders and caring for loved ones with eating disorders	Expert input and practical advice from the SLAM psychologists. Hearing from Joyce and Hannah gave hopeThe organisers are truly wonderfulAs well as the excellent input from the staff the contributions from others carers were invaluableVery experienced staff I thought they were excellentBeing guided by professionalsRegularity and attendance by SLaM team		
New learning acquired through the workshops	The great practical tips and encouragement. Knowing that it's okay to make mistakesCommunication tipsDiet, fun foods, different styles,Each session wa really valuable and helped me enormouslyI learnt so much about EDs and ne ways to support my loved one		
Workshop structure	Good structureWhilst structured, the sessions allowed for open discussionLiked opportunity to talk in breakouts		
Ideas for future workshops	I would like to start each workshop with 'hot spot' time, going round the meeting and giving each member opportunity to speakMore time to practise some of the communication skills in breakout groupsFeel that 'weight' is always too difficult to talk about as a real measure of recoveryneeds to be more integralMore men involved		

This figure aligns with somewhat with findings that 22.9% of people with anorexia nervosa may also have ASD/ASD traits reported by Huke and colleagues (Huke et al., 2013) and the large-sized (d = 1.065) increase in ASD traits, measured using the AQ in Westwood and colleagues' review (Westwood et al., 2016). Neurodiversity is therefore important to consider when running workshops. It may be that online workshops remove social barriers to accessing workshop learning outcomes and bring the social situation more into the control of the attendee. For example, they could turn off their camera if this felt more comfortable. We didn't systematically record whether those scoring over the cut-off on the AQ10 did this more than others, but it might be something to explore in future work. Although some supporters fed back that they preferred it when cameras were all on, online workshops possibly offer the opportunity to create a more inclusive space. Again this is something we could explore in future work. A further point in this context is that material in

the skills workshops often talks about recovery and how to communicate with loved ones in ways that promote recovery. However, given that people with ASD and EDs may see their pathway to recovery differently to neurotypical peers (Sedgewick, Leppenen, Austin & Tchanturia, 2021), this material might need more consideration. Future work could involve learning more about potential adaptations by speaking with neuro-diverse dyads of supporters and their loved ones.

An important issue with online provision is that it excludes those without access to a computer/smart device and the Internet. It may not be appropriate for a supporter to join a workshop from a shared computer in an open public space like a library as a means of overcoming this barrier to access. One way of overcoming this could be to invite these supporters to attend using a computer available in the recovery college in the hospital setting and to cover their travel costs to make this possible. A further point is that some people may just not like attending workshops online and therefore it might be

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necessary to support these individuals through in-person meetings.

4.1 | Limitations

This is not a systematic audit and while we had some funding to offer supporters gift vouchers after completing the outcome measures, most (n = 61, 76%) did not respond to the post-workshop questionnaire. This means we only know how the workshops impacted a subgroup of supporters and therefore the feedback may not represent all those who attended. Conversely, we conducted independent t-tests and a chi-square to explore whether any of the demographic or clinical variables, or scores on the CASK at the start of the workshops differed between those who completed the measures at the start of the workshops, compared to those who also completed them at the end of the workshops. There were no significant differences between these groups which potentially suggests that those who provided follow-up data do not differ from those who didn't.

We attempted to increase uptake of the end of workshop measures through various means. We sent several prompts and reminders and explained how important feedback was to our practice and service development. In future work, we might potentially offer a certificate of completion provided after feedback is given to increase completion rates. We could also provide a brief visual analogue scale in the form of a poll at the end of each workshop to collect data across the workshop series.

A further limitation to this work is that the CASK doesn't have a subscale on meal support skills and therefore it was difficult to measure the possible benefits of the session on nutrition. In future work, we will include items on meal support skills to understand this component of skills-based learning better.

Similar to the majority of supporters in Hannah et al.'s (2021) review, most supporters who opted into our workshops and completed the outcome measures were white British, female parents. Next time, we could work more closely with individual therapists within the service to identify more cases where it might be useful to involve more males, friends, siblings, children and partners. However, what this work has shown through the observed increase in carer skills and the positive feedback from supporters and facilitators is that it is possible to work together in a mixed group of supporters who are not just parents and whose loved ones are accessing different parts of the service (wait-list, outpatient, day-patient, inpatient). What worked well in achieving this was taking note at the start of the workshop series (1) supporters'

relationship to their loved one, and (2) the symptoms experienced by supporters' loved ones. We then made sure that we gave space for the different roles that supporters might have in their loved ones' lives, and discussed a range of behaviours, including restriction, binging, purging, excessive exercise, self-harm and other comorbidities like depression and anxiety. This is an important way of reaching a wider group of supporters and making the workshops more accessible.

To conclude, despite these limitations, as a multidisciplinary team of clinicians, researchers and experts by experience, we feel the strengths outweigh the challenges of delivering workshops for supporters online. Taking our learning into account, and in keeping with the widespread trend in healthcare towards more virtual care (Wosik et al., 2020), we will continue to offer the workshops in this virtual format. While it is important to note our analyses are purely exploratory, given the small number of individuals who provided data at follow-up, we think this evidence lends itself to us continuing with this approach even though the pandemic-related physical distancing restrictions have ended in the UK.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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